


Behavior	Strategies and Coping Skills for Individuals with PWS	
Aggression	Aggression is often a result of anxiety. Taking space is the number one coping skill for kids who become easily overwhelmed and react aggressively. Teaching your child to recognize when he or she needs to walk away and defuse is an invaluable skill that will have lifelong benefits.	
Anxiety	Anxiety and PWS go hand-in-hand. Our kids live every day battling anxiety that ranges from mild to crippling depending on the situation. Even the most anxious child in the most stress provoking situation can rise above and face their fears. We find that the best coping tools are encouraging communication about triggers and patterns, establishing calming day-time and night-time routines, showing positive examples, and praising strength and bravery. Also, take note of places and experiences that bring your child joy. During times of stress, talk to your child in detail about these places, and over time ask him or her to visualize these experiences on his or her own. This skill teaches decompression and mood stabilization.	
Compulsion & Obsessive Tendencies	Obsessive and compulsive behaviors are very common. Collecting, hoarding, tics and vocalizations can be signs of increasing anxiety. Routines and predictable environments can decrease these behaviors. For hoarding behaviors, consider a system where your child donates two items back for every new item collected.	
Emotional Outbursts	Outbursts can occur for a various reasons; often, a change in routine and unmet expectations can lead to a tantrum or meltdown. Keeping a routine and clear expectations can minimize the occurrences of outbursts. The top ten things to remember when you are managing a behavioral meltdown in public are: (10) THIS IS NORMAL (9) Don't be embarrassed (8) Perform a risk assessment (7) Take a breath and step back (6) Stay calm, look neutral, and stay present (5) Avoid "no" and "can't" (4) Give a simple direction, and then time and space (3) Let it go (2) Debrief after the event (1) Take care of yourself!	
Food Seeking	Role playing and social stories teach your child what to expect in different environments and situations. Anticipating potential stressors and having your child play their way through them before they actually happen can decrease their stress when the actual event takes place. Keep this in mind around the holidays when routines around food change. <i>(See handout from our LivingHealthy with PWS Cookbook, Holiday Meal Preparation and Recipes.)</i>	
Non-Compliance	People with executive functioning disorder (common with a PWS diagnosis) have difficulty organizing and remembering steps and can struggle with following instructions. This can often be misunderstood as non-compliance. Until you are able to teach appropriate reactions to the appropriate situation, be aware that your child is experiencing the stress of someone going through an emergency. In some kids, a problem such as not being able to go on an activity, a change in plans, or losing a toy or item of clothing may result in a reaction that we believe to be "over the top" — but keep in mind that they are truly experiencing this high level of panic. The "How Big is My Problem?" chart (right) illustrates the problem solving difficulties experienced by people with EFD.	 <p>How Big is My Problem?</p> <ul style="list-style-type: none"> 5 Emergency (Red icon): You definitely need help from a grownup (fire, someone is hurt and needs to go to the hospital, a car accident, danger). 4 Gigantic problem (Orange icon): You can change with a lot of help (getting lost, hitting, kicking, or punching a friend, throwing or breaking things, bullying). 3 Big problem (Yellow icon): You can change with some help (someone is mean to you or takes something that is yours, a minor accident, needing help causing down). 2 Medium problem (Blue icon): You can change with a little help (feeling sick, tired, or hungry, someone bothering you, being afraid, needing help). 1 Little problem (Light green icon): You can change with a little reminder (not being line leader, not wanting a game, not taking turns, making a mess). 0 Glitch (Dark green icon): You can fix yourself (changing clothes, cleaning up toys, forgetting favorite toy or blanket).
Perseveration	Perseveration of thoughts, repetitive questions, concrete thinking, and an overall stubborn presentation can be extremely frustrating for a caretaker. It can be helpful to remember that they are attempting to manage their environment. A good technique is to write down as much as possible; writing down the answers to questions can be very helpful and is visual. Additionally, deep breathing calms the body, clears the mind, and allows us to face anxiety more effectively. It is difficult for children and adults with PWS to breathe deeply, so games can be used to teach this skill. Blowing bubbles or blowing up balloons are ways of ensuring that your child is taking a good, deep breath.	
Skin Picking	Skin picking is a common behavior seen in PWS, but the severity of this behavior varies greatly. Start by avoiding bug bites and cracking or breaking skin. Next, keep hands busy! Strategies that we use include (but are not limited to) pulling burlap, popping bubble wrap, or using fidget devices.	



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